National Program of Cancer Registries (NPCR) Program Standards, 2017 to 2022

A functional, NPCR-funded central cancer registry must be able to:

- Report cancer incidence trends by geographic area and provide cancer data in support of cancer control programs.
- Collect and report incidence, burden, and stage data that can direct targeted interventions and be used to evaluate the success of cancer prevention and screening programs.
- Identify disparities by age, gender, race and ethnicity, and geographic areas in cancer incidence, stage at diagnosis, and mortality.
- Create and maintain registry and state policies that support research uses of cancer registry data.

Goals of NPCR:

- Collection and dissemination of high quality data on all reportable incident cancer cases in a timely manner for the purpose of public health cancer prevention and control
- Improved and enhanced electronic reporting to central cancer registries.

In addition to the goals stated above, the goal for any of the NPCR Component 2 pilot public health surveillance projects is to identify the feasibility of and/or barriers to collection of new information on cancer cases through cancer registries in one of three focus areas:

- Cervical cancer precursor data and outcomes directly related to cervical cancer prevention programs
- Cancer screening and diagnostic follow-up data on breast and cervical cancer cases
- New or emerging cancer prognostic factors or risk assessment models

NPCR Short, Intermediate, and Long-term Outcomes

Short Term Outcomes
• Increased access to quality and timely cancer data for stakeholders, partners and researchers
• Increased use of electronic reporting of cancer cases to the central cancer registry.
• Meet established NPCR's National Data Quality and Advanced National Data Quality standards
• Increased use of NPCR cancer data
• Improved access to enhanced cancer surveillance data

Intermediate Outcomes
• Targeted cancer screening for populations at risk
• Utilization of data for evidence-based decisions
• Utilization of data for cancer prevention and tobacco control strategies at state and local levels
• Increase in flexibility and utility of the cancer registry infrastructure to meet new data needs for cancer prevention and control

Long Term Outcomes
• Increased survival for all cancers
• Decreased incidence, morbidity, and mortality for all cancers
• Reduced cancer risk e.g. tobacco, alcohol, UV exposure
• Increased collaboration with Chronic Disease Programs at state and local levels

NPCR will monitor and assess progress, results, and overall impact through:

a) The NPCR performance measures, outputs and program outcomes from both the Integrated Cancer Logic Model as well as the NPCR Program specific logic model.

b) The annual cancer data submissions for progress in meeting NPCR Program Standards, as well as timelines and completeness requirements.
c) Results of the NPCR Program Evaluation Instrument, the Data Quality Evaluation in conjunction with annual progress reports for a comprehensive view of grantee performance.

Key Performance Measures for NPCR Component 1 and 2 will include the following outputs from the NPCR Logic Model:

• Activities to evaluate and improve timeliness, quality, and completeness of cancer data.
• Status of infrastructure for increased and electronic reporting of cases.
• Timeliness of capturing cancer cases from facilities.
• Successful submission of electronic data files, according to the timeframe and content established by CDC, to the NPCR Cancer Surveillance System (CSS).
• Meeting NPCR standards as outlined in NPCR Program Standards and evaluated by annual reports and Program Evaluation Instrument survey results.
• Creation and maintenance of registry and state policies supportive of research uses of central cancer registry data.
• Data dissemination and data use through the development of surveillance reports and other products that identify and report on the cancer burden and trends by age, gender, race/ethnicity and geographic area in support of health equity initiatives, cancer control programs, and public health practice.

NPCR Program Standards (Strategies)

The following strategies are defined as CDC's Program Standards for the National Program of Cancer Registries (NPCR). These standards are based on the legal authority provided to the CDC under the Public Health Service Act (Title 42, Chapter 6A, Sub-Chapter II, Part M, § 280e) and subsequent amendments, and apply to all reportable cancers as defined in the Act and amendments. These standards may change during the project period of the cooperative agreement.

Strategy 1: Program Collaboration

Support collaboration across CDC's NPCR, National Breast and Cervical Cancer Early Detection Program (NBCCEDP), and National Comprehensive Cancer Control Program (NCCCP as well as other chronic disease programs.

- The central cancer registry actively collaborates in the state's comprehensive cancer control planning efforts.
- The central cancer registry establishes a working relationship with other cancer control programs, including cancer screening programs and tobacco control programs, to assess and implement cancer control activities.
- The central cancer registry establishes and regularly convenes an advisory committee to help build consensus, cooperation, and planning for the registry and to enhance chronic disease program coordination and collaboration. Representation should include key organizations and individuals within (such as representatives from all cancer prevention and control components and chronic disease programs) and outside the program (such as hospital cancer registrars, the American Cancer Society, American College of Surgeons liaison, clinical-laboratory personnel, pathologists, and clinicians). Advisory committees may be structured to meet the needs of the state or territory, such as the comprehensive cancer control program committee structure, an advocacy group, or a focus group.

Strategy 2: External Partnerships

Convene, support, and sustain partnerships and networks necessary to support implementation of cancer program priorities and activities.

- Establish and convene an advisory committee to help enhance and use the central cancer registry data for prevention and control of cancer and other chronic diseases, and coordinate and collaborate with other cancer programs.
- Use the advisory committee to develop and refine quality improvement initiatives.
- Establish and promote greater awareness and use of the cancer registry data.

Strategy 3: Cancer Data and Surveillance

Legislative Authority

- The state or territory has a law authorizing a population-based central cancer registry.
- The state or territory has legislation or regulations that support Public Health Service Act Title 42, Chapter 6A, Sub-Chapter II, Part M, 280e, authorizing the NPCR.

Administration and Operations

- Hire or retain staff sufficient in number and expertise to manage, implement, and evaluate the central cancer registry, as well as use and disseminate the data. Core staff must fill the roles of program director, project director, principal investigator, quality assurance or quality control manager, and education and training coordinator.
- The central cancer registry maintains an operations manual that describes registry operations, policies, and procedures. At a minimum, the manual contains—
    1. The reporting laws and regulations.
    2. A list of reportable diagnoses.
    3. A list of required data items.
    4. Procedures for data processing operations, including procedures for—
        a) Monitoring timeliness of reporting.
        b) Receipt of data.
        c) Database management, including a description of the registry operating system software. This may be accomplished by citing a software vendor's Web site and documentation.
        d) Conducting death certificate clearance.
        e) Implementing and maintaining the quality assurance or quality control program, including procedures for—
            i. Conducting follow-back to reporting facilities on quality issues. These procedures include rules for identifying when action or further investigation is needed.
            ii. Conducting record consolidation.
            iii. Maintaining detailed documentation of all quality assurance operations.
            iv. Education and training.
        f) Conducting data exchange, including a list of states with which case-sharing agreements are in place.
        g) Conducting data linkages.
        h) Ensuring confidentiality and data security, including disaster planning.
        i) Data release, including access to and disclosure of information.
        j) Maintaining and updating the operations manual.
    5. Management reports that include processes and activities to monitor the registry operations and database.
    6. An abstracting and coding manual that is made available to and used by reporting sources that abstract and report cancer cases.

Data Collection, Content, and Format

- Central cancer registries must collect and submit data for all reportable cancers and benign neoplasms, including at a minimum, primary site, histology, behavior, date of diagnosis, race and ethnicity, age at diagnosis, gender, stage at diagnosis, and first course of treatment, according to CDC specifications and other information required by CDC.

- For all CDC-required reportable cases, the central cancer registry collects or derives all required data items using standard codes prescribed by CDC.

- Regardless of residency, the central cancer registry collects data on patients who were diagnosed or received the first course of treatment in the registry's state or territory.

- The central cancer registry uses a standardized, CDC-recommended data exchange format to transmit data to other central cancer registries and CDC.

Data Quality Assurance and Education

- The central cancer registry has an overall program of quality assurance that is defined in the registry operations manual. The quality assurance program includes, but is not limited to—

    1. A designated certified tumor registrar (CTR) is responsible for the quality assurance program.

    2. Quality assurance activities should be conducted by qualified, experienced CTRs or CTR-eligible staff.

    3. Data consolidation procedures are performed according to the central cancer registry protocol and nationally accepted abstracting and coding standards.

    4. At least once every five years, casefinding and re-abstracting audits are conducted from a sample of source documents for each hospital-based reporting facility. This may include external audits by CDC or SEER.

    5. Routine audits of a sample of consolidated cases are performed by the central cancer registry.

    6. Feedback is provided to reporting sources on data quality and completeness.

- The central cancer registry has an education program that is defined in the registry operations manual. The education program includes, but is not limited to—

    1. Training for central cancer registry staff and reporting sources to ensure high-quality data.

    2. A designated education and training coordinator who is a qualified, experienced CTR.

    3. Where feasible, the education and training coordinator may be regionally based, allowing applicants to collaborate to identify one applicant to provide the education and training coordinator activities to be carried out in a region.

Data Submission

- The central cancer registry annually submits data files to the NPCR Cancer Surveillance System (CSS) that meet the reporting requirements outlined in the NPCR CSS Submission Specifications document and meet criteria for publication in *United States Cancer Statistics.*

- In appropriate data submission years, when the central cancer registry data file meets specified data completeness and quality standards, the central cancer data are included in the *Cancer in Five Continents* publication.

- The central cancer registry participates in all CDC-created and hosted analytic datasets and Web-based data query systems, according to the annual NPCR CSS Data Release Policy.

Data Use and Data Monitoring

- Within 12 months of the end of the diagnosis year with data that are 90% complete, the central cancer registry produces preliminary pre-calculated data tables in an electronic data file or report of incidence rates, counts, or proportions for the diagnosis year by SEER site groups to monitor the top cancer sites within the state or territory.

- Within 24 months of the end of the diagnosis year with data that are 95% complete, the central cancer registry, in collaboration with local cancer control programs, produces the following electronic reports—

    1. Reports on age-adjusted incidence rates, stage at diagnosis, and age-adjusted mortality rates for the diagnosis year using SEER site groups and, where applicable, stratifying by sex, race, ethnicity, and geographic area.

    2. Biennial reports providing data on stage and incidence by geographic area, with an emphasis on screening-amenable cancers and cancers associated with modifiable risk factors, such as tobacco, obesity, and human papillomavirus (HPV).

- The central cancer registry ensures annual use of cancer registry data for public health and surveillance research purposes in at least five of the following ways—

    1. Comprehensive cancer control.

    2. Detailed incidence and mortality by stage and geographic area.

    3. Collaboration with cancer screening programs for breast, colorectal, or cervical cancer.

    4. Health event investigations.

    5. Needs assessment and program planning, such as Community Cancer Profiles.

    6. Program evaluation.

    7. Epidemiologic studies.

- The central cancer registry submits a success story to CDC at least annually detailing how registry data have been used to impact public health.

Electronic Data Exchange

- The central cancer registry is required to adopt and use standardized, CDC-recommended data transmission formats for the electronic exchange of cancer data (see CDC NPCR Electronic Reporting and Data Exchange Guidance). Registries should promote the use of these formats by reporting sources that transmit data to the registry electronically. CDC-recommended data exchange formats include—

    1. Hospital reporting: The NAACCR record layout version specified in year-appropriate *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary.*

    2. Anatomic pathology laboratory reports: NAACCR's *Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting* (version 2.2 or higher).

    3. Non-hospital sources using electronic medical records: Integrating the Healthcare Enterprise (IHE) Provider Reporting to Public Health-Cancer Registry (PRPH-Ca) Profile.

- For hospitals reporting to the central cancer registry, increase the percentage reporting electronically every year to meet the standard of all hospitals reporting electronically by the end of the five-year project period to reach a goal of 100% of all hospitals.

- For non-hospital facilities reporting to the central cancer registry, increase the percentage reporting electronically every year to meet the standard of at least 80% of these facilities reporting electronically by the end of the five-year project period.

- The central cancer registry uses a secure Internet-based, FTP, https, or encrypted e-mail mechanism to receive electronic data from reporting sources.

- The central cancer registry has a plan in place for receiving and processing data from electronic medical records over the five-year project period in accordance with Meaningful Use practices.

- The central cancer registry should submit the NPCR Hospital, Pathology Lab, and Physician Reporting Progress Report form with the Annual Report.

Strategy 4: Community Level Interventions and Patient Support

Disseminate cancer surveillance data with NCCCP and NBCCEDP programs, and other organizations and agencies as identified by the registry's advisory committee, to support community-level and patient support interventions.

Strategy 5: Health Systems Change

Linkages

- The central cancer registry links with state death files at least every year and incorporates results on vital status and cause of death into the registry database.

- The central cancer registry should link with the National Death Index annually, and incorporate results on vital status and cause of death into the registry database.

- The central cancer registry links with the state breast and cervical cancer early detection program at least once a year to identify potentially missed cases, reconcile differences between the two systems, and update appropriate data fields to capture post-linkage information.

- The central cancer registry links with the Indian Health Service (IHS) Administrative Database at least every five years. Central cancer registries with IHS Contract Health Service Delivery Area counties link their records with patient registration records from IHS annually.

- The central cancer registry uses linkages to address gaps identified in data quality and completeness or to improve the utility of the data. Potential sources of information include—

    1. Statewide electronic health files for casefinding and completeness of required data items.

    2. Claims data for casefinding and completeness of required data items.

    3. Census data (or similar) for socio-demographic variables.

    4. Birth records for demographic information.

    5. Department of Motor Vehicle records for demographic information.

    6. Voter registration files for demographic information.

Strategy 6: Program Monitoring and Evaluation

Data Completeness, Timeliness, and Quality

- Data being evaluated for the National Data Quality Standard (formerly known as the 24-Month Standard) must meet the following five data quality criteria—

    1. Data are 95% complete, based on observed-to-expected cases as computed by CDC.

    2. There are 3% or fewer death-certificate-only cases.

    3. There is a 1 per 1,000 or fewer unresolved duplicate rate.

    4. The maximum percentage missing for critical data elements are—

a) 2% age.

b) 2% sex.

c) 3% race.

d) 2% county.

5. 99% pass a CDC-prescribed set of standard edits.

- Data being evaluated for the Advanced National Data Quality Standard (formerly known as the 12-Month Standard) must meet the following four data quality criteria—

  1. Data are 90% complete, based on observed-to-expected cases as computed by CDC.

  2. There is a 2 per 1,000 or fewer unresolved duplicate rate.

  3. The maximum percent missing for critical data elements are—

     a) 3% age.

     b) 3% sex.

     c) 5% race.

     d) 3% county.

  4. 97% pass a CDC-prescribed set of standard edits.

- Annually increase case reporting by urologists, dermatologists, and gastroenterologists, as required by state law, to demonstrate continuing progress and improvement by the end of the five-year project period.

- Annually increase case reporting by medical oncologists, radiation oncologists, and hematologists, as required by state law, to demonstrate continuing progress and improvement by the end of the five-year project period.

- The cancer registry participates in the National Interstate Data Exchange Agreement to the extent possible, and exchanges data with all bordering central cancer registries and other central registries most likely to yield missed cases. Data exchange must meet the following minimum criteria—

  1. Occurs within 12 months of the close of the diagnosis year.

  2. Occurs at least twice a year.

  3. Includes all cases not exchanged previously.

  4. Includes all CDC-required data items.

  5. 99% of data pass a CDC-prescribed set of standard edits.

- The central cancer registry is required to complete and submit the NPCR Program Evaluation Instrument (PEI) as directed.